



Help Us Understand More About Inherited Cancer Risk



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What is the Northwest Cancer Genetics Network (NWCGN) Registry?

The Northwest Cancer Genetics Network (NWCGN), funded by the National Cancer Institute, is a new resource to help researchers answer important questions about inherited risks for cancer.

Information will be collected from people at all levels of risk from across the Northwest and entered into a confidential database. This information will be combined with information from other centers to create a national registry that scientists will be able to use for future research on cancer. As specific cancer research studies are developed locally and across the country, the NWCGN will invite eligible people enrolled in the registry to participate.

What are some benefits of being included in the NWCGN?

- ♦ You can help researchers and society learn more about genetics and cancer.
- ♦ You will be informed about special research studies for which you are eligible.
- ♦ You will receive regular updates on research on cancer and genetics.

Who can participate in the NWCGN?

We are seeking information from people who are at different levels of risk for developing cancer, from very low to very high risk, in order to better understand why cancer occurs. Interested persons between the ages of 18 and 74 are initially eligible to participate in the NWCGN.

The specific groups include:

1. People who have developed cancer and their close relatives
2. People who are concerned about developing cancer
3. People who have no known risk factors for developing cancer

Volunteers like you will be at the core of this network. The quality of the research depends on having as many individuals participate as possible. By being a part of the Cancer Genetics Network, you will be an important partner in the battle against cancer.

What will participants in the NWCGN be asked to do?

Participants will be asked about their medical and family history. Initial enrollment in the study occurs by telephone and takes about 15 minutes. Periodically, you will be contacted with a follow-up survey to make sure the information stays up to date. Researchers will use the NWCGN database to identify individuals for further studies.

Depending upon your family or medical history, you may be asked to participate in specific research projects. These projects may include additional questionnaires, educational activities, a blood sample, or providing permission to review certain medical records. When study opportunities come up for which you are eligible, you will be asked if you are interested in participating. You can always decline.

How is my confidentiality protected?

Keeping information confidential is an essential part of the registry. Participation in the registry and any personal information you provide will remain strictly confidential as required by law and our research protocols. Any information that can identify you will be separated from any other information before it is entered in the database. Your name will never be used without your permission. If any researcher wants to invite you into a study in which additional information will be collected, a member of the local network staff will first contact you.

What are some of the questions that the NWCGN will try to address?

Scientists will use the NWCGN to answer questions about cancer and genetics. Examples of questions that researchers may want to study include:

- ♦ How common are the inherited genetic changes that cause cancer?
- ♦ Why do some people with inherited genetic changes develop cancer and others do not?
- ♦ How does a person's lifestyle interact with these genetic changes to cause or prevent cancer?
- ♦ How can we use our new knowledge to help prevent cancer?
- ♦ How can we use our new knowledge to help detect cancers early?
- ♦ How can we improve cancer treatments?
- ♦ How can people cope better with cancer and cancer risk?

Who is conducting this study?

The NWCGN is a collaborative project of the Fred Hutchinson Cancer Research Center and the University of Washington School of Medicine. Other NWCGN partners are the Washington State Department of Health, the Providence Health System, the Pacific Northwest Regional Genetics Group, and the Cancer Information Service. For more information, contact the NWCGN project line at 1-800-616-8347 or check the website at <http://www.fhcr.org/cipr/cgn>

How can I participate in the NWCGN?

For additional information, contact:

NWCGN

1100 Fairview Avenue North, MW801 · Seattle, WA 98109-1024

Toll-free: 1-800-616-8347 · <http://www.fhcr.org/cipr/cgn/>

Have more questions about cancer?

For additional information on cancer, contact the Cancer Information Service, funded by the National Cancer Institute at 1-800-4-CANCER.